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Supports and Services for Persons with Disabilities in Canada: Requirements and Gaps

In this 17th edition of the CCSD's *Disability Information Sheets*, we provide data on requirements for supports and services among Canadians with disabilities, as well as information on gaps in these supports and services. Information in this issue is based on a longer report entitled, *Supports and Services for Adults and Children Aged 5-14 with Disabilities in Canada: An Analysis of Data on Needs and Gaps*. This longer report was commissioned by the Federal-Provincial-Territorial Ministers Responsible for Social Services and released on December 3, 2004. (www.socialunion.ca/pwd_e.html)

All the data for this *Information Sheet* and the longer report on which it is based were derived from the Participation and Activity Limitation Survey of 2001 (PALS). PALS is a post-Censal survey of persons with disabilities and contains rich information on such things as disability type and severity level. Unfortunately, PALS data do not include information on people in the Yukon, the Northwest Territories, or Nunavut.

Supports and Services for Persons with Disabilities

Many Canadians with disabilities require some type of support or service related to their disability. These supports and services can cover a broad range, from something relatively minor and fairly inexpensive to something quite complex and rather costly. In some instances, what is required is an item or a service that must be purchased – such as a wheelchair, a hearing aid, help with household duties, or a tutor – while in other instances what is required involves a change in practice – such as how buildings are constructed or having employers allow a job redesign and modified work hours.

Regardless of the complexity or cost of the requirement, a lack of these supports or services can create serious barriers to full participation for persons with disabilities. In this *Information Sheet*, we examine requirements for and unmet needs in two select areas: assistive aids and devices and help with daily activities.[1] This is not an exhaustive examination of all areas in which supports and services are required, nor do we provide a global estimate of the number of individuals who require any supports and services.

Assistive Aids/Devices:

Requirements for Assistive Aids and Devices

The majority of Canadians with disabilities require some type of assistive aid or device related to their disability.

- Among children aged 5 to 14 with disabilities, over two-thirds (68%) require some type of aid or device.[2] This represents 104,840 school-aged children.
- Among working-age adults (15 to 64 years) with disabilities, just over half (53%, representing 1,043,140 persons) have such a requirement.
- Among seniors with disabilities (those aged 65 and older), two-thirds (66%) require some type of assistive aid or device, representing 965,310 individuals.

The likelihood of requiring aids and devices increases with the severity of the disability. Among adults (aged 15+) with disabilities, for example, the rate of requirement for aids and devices increases from 37% for those with mild disabilities to 89% among those with very severe disabilities.[3]

A similar pattern is found among children aged 5 to 14 with disabilities. The likelihood of requiring an aid or device increases from 51% for those with mild disabilities, to 89% among those with very severe disabilities.[4]

Among adults, the most commonly required aids/devices are those related to *mobility* disabilities. This is not surprising, given the fact that mobility disabilities are the most prevalent type of disability among adults, affecting about 72% of all adults with disabilities. The most commonly required aids/devices are:

- cane or walking stick required by 679,560 adults (mobility disability);
- glasses required by 520,170 (seeing);[5]

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[1] Supports and services for adults at work and for children and adults at school will be addressed in coming issues.

[2] Children under 5 are not included in this analysis because the PALS only asked questions about assistive aids and devices for children aged 5 and older. It is often difficult, if not impossible, to determine the extent of a very young child's requirements for many types of supports and services.

[3] Rate of requirement for assistive aids and devices for adults with disabilities by severity level: mild disability, 37%; moderate disability, 57%; severe disability, 71%; and very severe disability, 89%.

[4] Rate of requirement for assistive aids and devices for children with disabilities by severity level: mild disability, 51%; moderate, 64%; severe, 78%; and very severe, 89%.

[5] This does not include persons who require eyeglasses/contact lenses which completely correct their vision problems.

- grab bars or bathroom aids required by 501,980 (mobility);
- hearing aids required by 397,970 (hearing);[6]
- other aids/devices required by 378,220 (for "other disability types");[7]
- walkers required by 294,410 (mobility);
- orthopaedic footwear required by 227,530 (mobility);
- braces or supportive devices required by 204,480 (mobility).

Among children, the most commonly required aids/devices are those related to *learning* disabilities:

- specialized computer required by 40,280 children (for learning disabilities);
- tutor required by 39,050 (learning disabilities);
- recording equipment required by 10,450 (learning disabilities);
- talking books required by 10,340 (learning disabilities);
- hearing aids required by 10,200 (hearing).

Unmet Needs for Assistive Aids and Devices

Among adults with disabilities who require some type of aid or device, two-thirds have their needs fully met (1,351,450 out of 2,008,460 adults with disabilities). However, one-third (657,000) have unmet needs.

Children with disabilities are less likely than adults to have their needs for assistive aids/devices fully met. Just a little over half (54%) of children with disabilities who require some type of aid/device have what they need, while just under half (46%) have unmet needs.

These data show that those most in need – that is, those with the most severe disabilities – are the least likely to have their needs met.

As the severity of the disability increases, so does the rate of unmet needs. Among adults with disabilities, 18% of those with mild disabilities have some type of unmet need for an aid/device, compared with 50% among those with very severe disabilities.[8]

Among school-aged children with disabilities, the spread is even greater: 20% of children with mild disabilities having an unmet need, compared with 69% of children with a very severe disability.[9] These data show that those most in need – that is, those with the most severe disabilities – are the *least likely* to have their needs met.

[6] This figure underestimates the actual number of individuals who require hearing aids since the PALS file does not permit the identification of all individuals who require a hearing aid but do not have one, or who do not have the correct one.

[7] This includes aids/devices of an unspecified nature for unspecified disabilities.

[8] The rate of unmet need among adults with disabilities by severity level is: 18% for those with mild disabilities; 28%, moderate; 36%, severe; and 50% for adults with very severe disabilities.

[9] The rate of unmet need among children with disabilities by severity level is: 20% for those with mild disabilities; 42%, moderate; 54%, severe; and 69% for children with very severe disabilities.

Among adults with disabilities, the greatest *number* of people reporting an unmet need required "other aids or devices not specified."[10] In particular, the *greatest unmet need* was for "other hearing-related aids or devices" (144,720). This number likely includes a high proportion of people who require a hearing aid but either do not have the type they need or have no hearing aid at all.

Aids or devices designed for mobility disabilities constitute the greatest overall number of unmet needs. Again, this is largely due to the high proportion of adults with mobility disabilities. Overall, the largest *number* with unmet needs for aids/devices are:

- 83,600 adults have unmet needs for grab bars or bathroom aids (mobility);
- 43,710 for canes or walking sticks (mobility);
- 47,630 for scooters (mobility);
- 44,070 for eyeglasses or contact lenses (seeing);
- 36,380 for lifts or lift-type devices (mobility);
- 35,420 adults have unmet needs for grasping tools and reach extenders (mobility).

The highest *rates* of unmet need among adults[11] – that is, the percentage of those who require an aid/device but have an unmet need – are for:

- communications boards, such as Bliss – 60% (speech);
- scooters – 52% (mobility);
- motorized wheelchairs – 52% (mobility);
- voice amplifier – 48% (speech);
- talking books – 47% (learning aids);
- voice-recognition software – 46% (learning);
- portable spell checkers – 39% (learning);
- home computers – 38% (learning);
- lifts and lift-type devices – 37% (mobility).

Some mobility-related aids/devices contribute a great deal to the overall *number* with an unmet need and also to a high *rate* of unmet need. Included in this are scooters and lifts/lift-type devices, both of which tend to be among the more expensive aids/devices. For example, according to the *Price Survey of Assistive Devices and Supports for Persons with Disabilities*,[12] scooters cost, on average, just under $4,000. Aids/devices related to learning disabilities and to speech-related disabilities also contribute to high rates of unmet need.[13]

[10] This suggests that there are many aids/devices that are important to persons with disabilities but which were not specifically listed in the PALS. In the case of unspecified aids related to hearing disabilities, we have reason to believe that many of those reporting an unmet need were individuals who require hearing aids. Due to a flaw in the questionnaire, however, many individuals who needed, but did not have, hearing aids were unable to specify that particular device, and they likely selected "other hearing" instead.

[11] These are the highest rates for specific devices cited. There are also high rates of unmet need for "unspecified devices."

[12] By Aaron Spector, Applied Research, HRDC, December 2003. (http://publications.gc.ca)

[13] The highest rates of unmet need by disability type are found among those who have developmental, learning, psychological, speech, or memory disabilities.

Among children with disabilities, the greatest *number* of children with an unmet need involves those who require aids/devices aimed at learning disabilities:

- tutor – unmet need for 11,000 children (learning);
- computer – for 8,280 (learning);
- voice-activated or synthesis software – for 4,150 (learning);
- talking books – for 2,700 (learning);
- voice amplifier – for 2,270 (speech);
- recording equipment – unmet need for 2,120 children (learning).

Among children with disabilities, the following aids/devices contribute to the highest *rates* of unmet need:

- computer to communicate – 63% (speech);
- voice-activated or synthesis software – 48% (learning);
- lift devices – 45% (mobility);
- tutor – 28% (learning);
- talking books – 26% (learning);
- orthopaedic footwear – 24% (mobility);
- computer – 21% (learning).

The highest rates of unmet need among children are for those who require aids/devices for their learning disabilities or speech disabilities and for those who require fairly expensive items such as lift devices – as was found with adults. The rate of unmet need is also fairly high among children who require orthopaedic footwear (24%), whereas among adults, only 13% had this need unmet. Since children have growing feet, this aid/device must be constantly upgraded, thereby making it a much more costly item than might first appear.

In fact, unmet needs may be more likely among any population for whom the nature of the needs change over time. This applies to growing children and to adults with disabilities that are progressive in nature, such as:

- muscular dystrophy (www.mdac.ca/)
- amyotrophic lateral sclerosis or ALS (www.als.ca/)
- Huntington Disease (www.hsc-ca.org/)
- Parkinson's Disease (www.parkinson.ca/)
- Alzheimer Disease (www.alzheimer.ca/)
- multiple sclerosis (www.mssociety.ca/).[14]

Reasons for Unmet Needs for Assistive Aids/Devices

Among adults, the two most prevalent reasons for having an unmet need were that the assistive aids/devices were "too expensive" (cited by 66% or 315,420 individuals) and that the aid or device was "not covered by insurance" (cited by 50% or 236,940 adults). (Note: Individuals often listed more than one reason.) It is also

[14] See *In Synchrony: Looking at Disability Supports from a Progressive Disability Function* (2003), which was produced in partnership by six national health charities: Muscular Dystrophy Canada, the Huntington Society of Canada, the Parkinson Society Canada, the ALS Society of Canada, the Alzheimer Society of Canada and the Multiple Sclerosis Society of Canada.

noteworthy, however, that 17% or 123,380 people said they "did not know where to obtain the aid/device" and 6% or 26,310 people indicated that the "aid/device was not available." This suggests that, in addition to cost barriers, there may also be information and availability barriers to obtaining needed supports and services.

Similarly, among children, the most prevalent reason for not having the required aids/devices was financial: 67% or 26,830 respondents said the device was "too expensive" and 53% or 21,190 said the aid/device was "not covered by insurance." Lack of information and lack of availability were also important: "did not know where to obtain the aid/device" was cited by 25% or 10,040 respondents, and "not available locally" was cited by 21% or 8,270.

Helpful Resources On-line:

Readers wanting to know more may find the following websites helpful:

- programs which provide supports and services for persons with disabilities: www.disabilityweblinks.ca.
- *Directory of Disability Organizations in Canada*, by the Canadian Abilities Foundation, lists contact information for a wide range of disability organizations in Canada: www.enablelink.org/
- accessible transportation services: www.enablelink.org/
- the Canadian Abilities Foundation's new *Access Guide Canada* lists accessible locations across the country: www.enablelink.org/agc/index.php
- a Government of Canada website provides a full range of information on disability-related programs and services: www.pwd-online.ca

Help with Daily Activities:

Requirements and Unmet Needs for Help with Daily Activities

Approximately 2.4 million adult Canadians with disabilities – 70% of adults with disabilities – require help with some type of daily activity due to their disability. The need for support with daily activities increases with severity level, from 47% of those with mild disabilities to 94% of those with very severe disabilities.[15] Among the daily activities listed,[16] the four most commonly requiring support are:

- heavy housework, required by 1,912,010 adults with disabilities;
- everyday housework, required by 1,261,360;
- getting to appointments, required by 1,264,340;
- meal preparation, required by 844,330.

[15] Among adults, the rate of requiring help with daily activities by severity level is: 47% of those with mild disabilities; 70%, moderate; 86%, severe; and 94% of those with very severe disabilities.

[16] Daily activities listed in PALS were: heavy housework; everyday housework; getting to appointments; meal preparation; personal finances; child care (This was asked only for those with children under 15 living with them); personal care; specialized nursing/medical treatment; and, help moving about the house.

Among adults requiring support with their daily activities, two-thirds (1,615,460) receive the help they need. Just over one-quarter (652,660) receive some of the help they need, but still require more; and about 5% (130,590) have none of the help they need.

In terms of sheer *numbers*, heavy housework (484,180 adults with an unmet need); everyday housework (340,050); getting to appointments (252,390); and meal preparation (141,380) contribute to the greatest unmet needs. This is largely a function of these activities being the most commonly required supports.

In terms of the *rate* of unmet need – which is more a measure of the success rate at getting what is needed – child care requirements are the most problematic: 40% or 25,130 individuals who require child care due to their disability have an unmet need. While there is a fairly low proportion of adults who have this requirement (remembering that this question was asked only of people who were living with children under the age of 15), this lack of success in obtaining a needed support service indicates an area for further study. Higher than average rates of unmet needs are also found among those who require specialized nursing care (29%) and help with heavy housework (27%). The lowest rates of unmet needs are for help with personal finances (13%) and meal preparation (16%).[17]

Among families of school-aged children with disabilities, 34% report that they require some type of household support or respite care due to their child's disability – for example, to attend to other family responsibilities, or to take time for personal activities. Overall, more than two-thirds of families of children with disabilities (51,980) who require such support have their needs go unmet.

As was found with assistive aids and devices, cost-related reasons are most often cited for the lack of support with daily activities: 52% indicated the help was "too expensive"; 27% cited "no informal help available"; and 27% said the help was "not covered by insurance".[18] However, a lack of information and lack of availability were also prominently cited – 25% "didn't know where to obtain help" and 11% said "help not available". (Note: Individuals often cited more than one reason for having their needs unmet.)

Who Provides Help with Daily Activities?

Perhaps the most critical finding in terms of needed help with daily activities is that the vast majority of that support is currently being provided by family and friends – for free. While people obtain help from a variety of sources, 63% said they receive some support for these activities from family members who live with them, and 42% obtain support from family members not living with them. In addition, 24% obtain some support

[17] As well, those with an unmet need for child care and for nursing care were most likely to have a completely unmet need – i.e., they did not have any support in this area at all. See the main report for more details.

[18] Women were more likely than men to report cost as the main reason for lack of supports. See the main report for more details.

from friends and neighbours, and only 24% obtain support from organizations or agencies. (Note: these percentages do not add up to 100% since people may obtain support from more than one source.)

Most individuals (70%) report receiving help for free; 33% said they or immediate family members pay for assistance; 2% report that family members not living with them pay for assistance;[19] 3% have assistance paid for by a home care program; and 3% report that some other public source pays for help with daily activities. While these categories are not mutually exclusive, 90% of individuals report having only one source to pay for the help they need with daily activities, and another 8% report having only two sources.

Among the 664,050 individuals who pay for the support themselves – that is, the 33% who report that they or immediate family members pay for at least some assistance with daily activities – only 8% said they are being reimbursed either fully or partially for these costs. Of those who are reimbursed, 46% receive some reimbursement directly from a level of government, 21% are reimbursed by a private health care plan, and 21% are reimbursed through a tax credit.

This finding, that a huge proportion of the necessary help with daily living activities is now being provided by family and friends, suggests that the formal infrastructure designed to provide such supports – i.e., organizations and agencies – in fact, serves only a fraction of those in need. As the baby-boom generation ages and the potential pool of informal help declines (on average, baby-boomers have fewer children than previous generations), demands on the formal infrastructure for help with individuals' daily activities will begin to skyrocket. And because very little of the help that is provided comes from or is paid for by any public source, these demographic changes should be of tremendous concern.

[19] This figure may be understated.

In the next issue of DRIP, we will explore data on employment and persons with disabilities using information from the PALS, WES and the Census and will include some provincial-level data on employment patterns from the Census.

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